

Testimony Before the Subcommittee on Criminal Justice, Drug Policy, and Human Resources Committee on Government Reform United States House of Representatives

Centers for Disease Control and Prevention Public Health Work Relating to Gynecological Cancers

Statement of

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Mr. Chairman and Members of the Subcommittee, good morning. I am Dr. Ed Thompson, the Chief of Public Health Practice for the Centers for Disease Control and Prevention (CDC).

Thank you for this opportunity to discuss CDC's public health work related to gynecologic cancers. Allow me to express at the very outset my gratitude to the Subcommittee for giving us the opportunity to talk to you about addressing the public health perspective surrounding gynecologic cancer.

The Types and Burden of Gynecologic Cancers in the United States

Gynecologic cancers are the uncontrolled growth and spread of abnormal cells originating in female reproductive organs that include the uterus, ovaries, cervix, vulva and vagina. According to the most recent CDC and National Cancer Institute (NCI) data included in the *United States Cancer Statistics (USCS): 2002 Incidence and Mortality* report:

- More than 71,000 women in the United States were diagnosed with a cancer affecting the reproductive organs; these data are from cancer registries that meet high quality data criteria and cover 93 percent of the U.S. population
- Over 27,000 women in the United States died from some form of gynecologic cancer; these death counts cover 100 percent of the U.S. population
- Endometrial cancer (cancer of the tissue that lines the uterus) is the most common gynecologic cancer
- Ovarian cancer is the most deadly gynecologic cancer

The U.S. cases (based on 93 percent of the U.S. population) and deaths (based on 100 percent of the U.S. population) for these cancers are as follows:

Endometrial (uterine) cancer: Cases: 34,478 Deaths: 6,853
Ovarian: Cases: 19,177 Deaths: 14,682
Cervical: Cases: 12,085 Deaths: 3,952
Vulvar cancers: Cases: 3,411 Deaths: 794
Vaginal: Cases: 1,069 Deaths: 378
Other: Counts: 970 Deaths: 432

Endometrial Cancer

Endometrial cancer is often associated with known risk factors. Women who: use estrogen replacement therapy (often used to treat menopause symptoms); use Tamoxifen and other selective estrogen receptor modulators; experience the onset of menstruation and menopause at early ages; are obese; carry the hereditary nonpolyposis colorectal cancer genetic abnormality; have polycystic ovarian syndrome; or have never been pregnant are at increased risks for developing endometrial cancer. Women who breastfeed or use combination oral contraceptives may have reduced risks for developing endometrial cancer. Currently, there are no screening tests for endometrial cancer. Most women survive this disease because of effective treatment strategies.

Ovarian Cancer

According to the CDC and NCI's USCS, ovarian cancer is the seventh most common cancer in women, and is the fifth leading cause of cancer death in women. Currently, half the women diagnosed with ovarian cancer die from the disease within five years. Ovarian cancer has been associated with certain risk factors. Factors that increase one's risk of developing ovarian cancer include the woman's age, family history of the disease, and the use of hormone replacement

therapy. Women who use oral contraceptives, have at least one child, breastfeed, or have undergone tubal ligation or a hysterectomy may have decreased risks for developing ovarian cancer. There is no reliable screening test that has been shown to reduce the risk of dying from ovarian cancer; however, several potential screening methods currently are being tested.

Cervical Cancer

Cervical cancer was once the leading cause of death for women in the United States; however, during the past four decades, incidence and mortality have declined significantly, primarily because of the widespread use of the Papanicolaou (Pap) test to detect cervical abnormalities. Regular Pap tests decrease one's risk for developing cervical cancer because they can detect precancerous cervical lesions at early, highly treatable stages. Cervical cancer is the only gynecologic cancer for which regular screening is recommended. The U.S. Preventive Services Task Force strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix. Approximately half of the cervical cancers currently diagnosed in the United States are in women who have never received a Pap test, and an additional 10 percent occur in women who have not been screened within the past five years.

Human papillomavirus (HPV) infection is the primary cause for the development of cervical cancer. Increased incidence of cervical cancer is observed in women who: have multiple sexual partners; initiate sexual intercourse at early ages; have a high number of full-term pregnancies (seven or higher); smoke cigarettes; or use oral contraceptives for extended periods of time (five years or more). The relationship between these risk factors and cervical cancer is not entirely understood..

Vulvar and Vaginal Cancers

Other cancers of the female reproductive system are less common. Vulvar cancer, for example, accounts for only four percent of cancers in the female reproductive organs. HPV infection and smoking increase a woman's risk for developing vulvar cancer. Vaginal cancer accounts for approximately three percent of cancers of the female reproductive system. Young women whose mothers took diethylstilbestrol (DES) during pregnancy are at greater risk for developing vaginal cancer. The drug was given to pregnant women between 1945 and 1970 as a precaution against miscarriage. It has been suggested that HPV infection and smoking may also increase a woman's risk for developing vaginal cancer. Currently, there are no effective screening tests for vulvar or vaginal cancer, so women at increased risk need to be monitored closely.

CDC's Activities to Reduce the Burden of Gynecologic Cancers in the United States

CDC supports several initiatives specifically designed to reduce the burden of certain gynecologic cancers. For many of these cancers, prevention and early detection are essential to survival. CDC's efforts largely are directed towards surveillance; screening (where recommended); public education and awareness; health care provider education and awareness; and research.

National Breast and Cervical Cancer Early Detection Program

CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which was established by Congress in 1991, helps low-income, uninsured, and under-served women gain access to lifesaving screening programs for early detection of breast and cervical cancers. The

national program currently provides screening support in all 50 States, the District of Columbia, 4 U.S. Territories, and 13 Tribes and Tribal organizations. Since 1991, the NBCCEDP has provided more than 2.9 million Pap tests and detected invasive cancers in more than 1,500 women. Testament to the benefits of prevention and early detection is the fact that in more than 38,000 women, cancer precursor lesions have been detected and treated since the program's inception. The NBCCEDP also provided diagnostic evaluation for an additional 38,000 precursor lesions for women referred to the program, as follow-up to abnormal results from screenings not provided by the program.

The NBCCEDP supports an array of strategies that include partnerships; public education and outreach; professional development; screening; tracking; follow-up; and case management services that work collaboratively to provide cervical cancer screening, diagnostic evaluation, and treatment referrals (where appropriate). The success of the program historically has depended on the complementary efforts of a variety of national organizations, as well as on state and community partners.

National Comprehensive Cancer Control Program

CDC's National Comprehensive Cancer Control Program (NCCCP) provides support in every State and the District of Columbia, as well as in several territories, Tribes, and Tribal organizations, to develop comprehensive cancer control plans. These plans serve as blueprints for developing and implementing cancer control activities. California and Florida have identified specific strategies in their cancer control plans to address the burden of ovarian and/or cervical cancer in local communities. In California, these strategies include: promoting referrals of ovarian cancer patients to clinical trials; promoting education and awareness within California's communities; and, supporting ovarian cancer research.

The program also provides funding specifically for ovarian cancer initiatives in West Virginia, Colorado, Alabama, Minnesota, New York, and Utah. Activities funded through these initiatives include efforts to increase healthcare provider education, public education, and awareness of ovarian cancer issues. In Alabama, the ovarian initiative focuses on enhancing the public's understanding of hereditary factors that increase the risk of developing ovarian cancer. West Virginia's "Raising Ovarian Cancer Awareness Initiative" enlists ovarian cancer experts to deliver outreach messages to women in high-incidence counties about the symptoms of ovarian cancer and the importance of gynecologic exams. Since implementing this initiative, the State has been able to demonstrate a 40 percent increase in participants' knowledge of the symptoms and risk factors for ovarian cancer.

National Program of Cancer Registries

Cancer registries collect information about incidence, diagnoses, treatment, and mortality. Data collected by cancer registries enable public health program planners to understand and address the cancer burden better, as well as evaluate the effectiveness of efforts to prevent, control, and treat cancer. CDC's National Program of Cancer Registries (NPCR), established in 1994, supports and promotes the collection and use of registry data in 45 States, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands. The NPCR currently collects surveillance data for all cancers, including cancers of the cervix, uterus, ovaries, vagina, and vulva as reported for Whites, African Americans, Asians/Pacific Islanders,

Hispanics, and American Indian/Alaskan Natives. Data collected through the NPCR often are used by States to create burden assessments that guide program planning, outreach, and education efforts. The CDC's NPCR complements the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) Registry program, which, prior to NPCR's establishment, collected cancer surveillance data for approximately fifteen percent of the U. S. population. Together, the NPCR and SEER programs collect cancer data for the entire U.S. population. These data are provided annually in the national United States Cancer Statistics report. This report can be accessed at http://www.cdc.gov/cancer/npcr/index.htm.

CDC's NPCR also is conducting Patterns of Care Studies that compare the quality of data concerning treatment and stage reported to nine NPCR registries, with data from the corresponding medical records. State tumor registries in California, Maryland, and New York are funded to support the special analyses of ovarian cancer treatment data in these medical record reviews. These studies are using population-based samples to estimate the proportion of patients in each state that received the recommended standard of care. Additionally, data on ovarian cancer outcomes and staging are being assessed by physician's specialty. Preliminary results are expected before the end of the year.

Cervical Cancer Education and Awareness Project

The CDC supports an education and awareness project through the National Organizations Strategies for Prevention, Early Detection, or Survivorship of Cancer in Underserved Populations program. The project's goal is to reduce cervical cancer incidence and mortality among working women by promoting increased cervical screening and annual follow up for women in unions. Several education and awareness brochures have been produced from focus group analyses. CDC has partnered with the National Education Association's Health Information Network to increase the circulation of their education and awareness materials among teachers and other support professionals.

Partnerships to Reduce the Burden of Gynecologic Cancers

The CDC has formed partnerships with other Federal and non-Federal organizations to improve prevention, early detection, and treatment of certain gynecologic cancers. An example of such collaboration is found in the development of *The Guide to Community Preventive Services*, which provides systemic reviews and recommendations for interventions. The task force responsible for this guide is multi-disciplinary, and includes perspectives that represent state and local health departments, managed care, academia, behavioral and social sciences, and others. This task force reviews and assesses the quality of available evidence on the effectiveness of community preventive health services, and develops recommendations for specific focus areas, including cervical cancer.

Another example of collaboration to reduce the burden of certain gynecologic cancers is the development of the *Family Healthware* Web-based assessment tool, supported by CDC, the National Institutes of Health, academia, and State health departments. The tool promotes the use of family history information to assess risk and determine prevention strategies. Specifically, the tool assesses familial risk for six chronic diseases, including ovarian cancer, and recommends

early detection and prevention strategies. Evidence strongly suggests that a positive family history of ovarian cancer increases one's risk for developing the disease.

The National Cervical Cancer Public Education Campaign encourages women to take action and get screened to prevent cervical cancer. Led by the Gynecologic Cancer Foundation and supported by partners that include the CDC, NCI, and the American Cancer Society, the educational campaign offers women and providers information about the causes of cervical cancer, as well as information about prevention and early detection. The campaign has developed educational brochures and patient presentations to help women understand cervical cancer and encourage appropriate screening and follow-up. The campaign also offers a resource list for women for obtaining cancer information and for identifying screening and patient support resources.

<u>CDC's Research Activities to Address the Burden of Gynecologic Cancers in the United States</u>

CDC has an active public health research program related to ovarian cancer. To guide the development of these ovarian cancer research activities, CDC sponsored workshops in 2000 and 2002 with outside experts in clinical and epidemiologic research, public health leaders from Federal and State agencies, and ovarian cancer survivors. These workshop participants identified key areas for research related to learning more about early symptoms and methods for earlier diagnosis as well as optimizing treatment and end of life care. In response to the recommendations from these workshops, the cancer epidemiology and applied research program at CDC has several ongoing studies to identify interventions that can improve the quality of life of women diagnosed with ovarian cancer. For example, research is focusing on when a woman seeks care and for what symptoms, how medical care providers respond to these symptoms; and what diagnostic practices shorten the time to diagnosis and can improve surgical evaluation and end-of-life care.

With regard to cervical cancer, CDC's program in cancer epidemiology and applied research is developing and evaluating behavioral provider and patient-based interventions aimed at increasing cervical cancer screening among Mexican women, African-American women, and low-income women. Through this research, we intend to provide evidence about effective, culturally sensitive methods to reach specific groups of women who have rarely or never been screened for cervical cancer. We also are conducting research on the attitudes, practices and training needs of providers of cervical cancer screening and follow-up using data collected through CDC's National Ambulatory Medical Care Survey and data collected about participants in CDC's NBCCEDP. In addition, CDC has been collecting data on Pap testing practices from two national CDC surveys, the National Health Interview Survey and the Behavioral Risk Factor Surveillance System, to monitor trends in Pap testing, understand the disparities in cervical cancer screening, and to identify women who are being over screened.

CDC's Publications Concerning Gynecologic Cancers in the United States

The CDC recently published several articles and a report related to cervical cancer screening. "Breast and Cervical Cancer Screening Among Mississippi Delta Women," published in the *Journal of Health Care for the Poor and Underserved* in 2004, describes screening practices and

behaviors among women in a region where cervical cancer mortality is considerably higher than in other areas.

"Adherence to Guidelines for Follow-up of Low-Grade Cytologic Abnormalities among Medically Underserved Women," published in a 2005 issue of *Obstetrics and Gynecology*, describes specific screening practices of health care providers participating in the NBCCEDP. Results from this study are used to develop strategies for educating NBCCEDP health care providers.

The National Breast and Cervical Cancer Early Detection Program: 1991-2002 National Report, released in 2005, is a CDC publication that describes screening successes and challenges.

Conclusion

Gynecologic cancers constitute a serious health problem in this country. Four of the five cancers mentioned today do not have an approved screening test. Our role at CDC is focused on risk reduction, early detection, surveillance, identifying and improving barriers to appropriate clinical practice, and enhanced survivorship. There is much work to be done in these areas for addressing all gynecological cancers. It is essential that all women in the United States, and the health care providers who treat them, have access to up-to-date, accurate information about these cancers. One way to improve access to good healthcare for women is through education and awareness campaigns for gynecologic cancer designed to increase knowledge and change behaviors. Any gynecologic cancer campaign should be population based, with an emphasis on underserved women and their healthcare providers. The campaigns should employ multiple strategies to reach all women in need and they should be evaluated and tested for effectiveness. Then, the most effective strategies should be widely disseminated through a comprehensive national campaign.

CDC has a strong presence in the field of gynecologic cancers, and is currently working in several critical areas. The CDC will continue to support:

- the National Breast and Cervical Cancer Screening Program, which provides access to cervical cancer screening to uninsured, poor, underserved women in this country;
- the National Comprehensive Cancer Control Program, which promotes the inclusion and implementation of ovarian cancer education and awareness initiatives in cancer control plans across the nation;
- the National Cancer Registries Program's ongoing activities to address gynecologic cancers through the population-based collection, analysis, and sharing of gynecologic cancer surveillance data;
- research to improve education and increase awareness for the public and health care providers, and improve and maintain the development and implementation of effective screening practices and interventions; and,
- partnerships with Federal, State, academic, and community organizations to improve gynecologic cancer experiences and outcomes.

Thank you again for this opportunity to speak with you about public health issues surrounding gynecologic cancers, and CDC's work related to these diseases. I am happy to answer any questions.